



# Creating Target Population Estimates Using National Survey Data

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Maternal and child health (MCH) programs target a wide variety of population groups for services. One targeted group, in particular, is children with special health care needs (CSHCN). Estimating the size of the population, including relevant subgroups is a core function of MCH/CSHCN programs.

This module was developed to assist state and local program staff in developing these estimates for this group.

This module will address:

- Describing target population characteristics
- Sources of data
- Developing indirect estimates of a target population
- Developing a state synthetic population estimate
- Exercises and Solutions
- References

## DESCRIBING TARGET POPULATION CHARACTERISTICS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Illuminating the characteristics of the population of interest is the first step toward estimating the size of the target population. Target populations may be defined by age and sex (e.g., teen family planning, adolescent health, etc.), program eligibility (e.g., children with special health care needs, SSI, school health clinics, Ryan White Fund, etc.) or income level (e.g., Healthy Start, Medicaid, etc.). Populations defined by race, age, sex or income can often be directly estimated using census data.

When population characteristics cannot be measured using Census data, topical sample surveys are the next best source of data. However, because we often do not have this type of locally collected data, more

complex estimation procedures are required such as synthetic estimation. (Refer to Module 3 for more detailed discussion of synthetic estimation.)

Estimating the population of children with special health care needs has been the biggest challenge for MCH programs. This population was chosen for the focus of this module because it exemplifies many of the issues we face in target population estimation.

## WHO ARE CHILDREN WITH SPECIAL HEALTH CARE NEEDS?

Children with special health care needs (CSHCN) include children with a wide variety of health conditions. Some of these children also have more than one condition. Estimation of the number of CSHCN may involve identifying:

- the prevalence of children with special needs as identified by state and federal programs,
- the prevalence of specific diseases and conditions in children,
- the prevalence of functional limitations among children,
- the proportion of children who require or need specialized services, and
- the proportion of children who are regarded by others as disabled.

Because *there is no data source from which a direct measurement of the size of this population can be estimated* and because of the diversity of definitions, no one method alone will completely provide an all-inclusive estimate of the prevalence of CSHCN. Therefore, averaging and/or summing multiple types of estimates may be required. Before we can create an estimate it is important to understand the variety of ways that this population may be defined.

The definition chosen can have major implications for the size of the population estimate as reflected in the following examples (McManus 1997):

- 31% of children have chronic physical conditions  
(1988 *Child Health Supplement to National Health Interview Survey*)
- 20% of children have chronic mental conditions  
(1988 *Child Health Supplement to National Health Interview Survey*)
- 7% of children have a limitation of activity  
(1994 *Child Health Supplement to National Health Interview Survey*)
- 2% of children have a limitation in activities of daily living  
(1978-1980 *National Health Interview Survey*)

There are three major approaches to defining CSHCN:

- Diagnosis-based,
- Function-based, and
- Service-based.

## Diagnosis-Based Approach

There have been widely differing estimates published on children with chronic illness/disability. Because there is no consensus from the research community on a definition, there is an emphasis on reporting single disease/condition prevalence or incidence. Newacheck and Taylor (1992) reported that published estimates range from 5% to more than 30%. They also reported that two or more conditions coexist in about 30% of affected children. In addition, undiagnosed conditions are not counted. Research has shown that there are commonalties in the experience of having a chronic condition, in addition to those specific to a particular condition. However, by focusing in on reporting the prevalence of conditions, the overall experience of the child and family is missed. In addition, when reporting the prevalence of conditions, it is important to distinguish between conditions that are acute, transient and/or self-limited from those which are lengthy in duration or more likely to be permanent. Therefore, knowledge about the length of time that the child has had the condition is critical to developing a prevalence measure which is meaningful to program planning for CSHCN.

## Function-Based Approach

Unlike diagnosis, limitations in function have a direct impact on the quality of life and use of resources by CSHCN. Therefore, estimating the prevalence of children with functional limitations can be more useful for program planning than diagnosis. Function may be categorized into four areas: mobility, self-care, communication and learning ability. Self-care and mobility impairments have been associated with lower rates of survivorship (Eyman, et al, 1990) and are the least prevalent among functional limitations in children. The most common functional limitations among children involve communication and learning ability.

Unlike diagnosis, the measurement of limitation is not available in the medical record and actual performance-based measurement is not available in most cases. National population estimates of functional limitation are obtained using standardized questionnaires. Two major surveys which collect this information for persons of all ages include the Survey on Income and Program Participation (SIPP) (<http://www.census.gov/hhes/sippdesc.html>) conducted by the U.S. Bureau of the Census and the National Health Interview Survey conducted by the National Center for Health Statistics (NCHS). Survey methods for measuring functional limitations are difficult to design due to the age-relatedness of functional limitations.

The major focus of SIPP is on income and the labor force. SIPP concentrates on children ages 6-14 and treats children ages 15-17 as adults. SIPP asks about: ability to perform activities of daily living (ADL's); the use of wheelchairs, canes, crutches and walkers; the ability to perform the functional activities of seeing, hearing, walking, running and using stairs; the ability to do regular schoolwork, and presence of a learning disability, mental retardation or some other developmental disability.

The National Health Interview Survey conducted a special survey on disability in 1994-95 (heretofore called NHIS-D). The NHIS-D included separate questions for children under age 4 and questions very similar to SIPP for children ages 5-17. Measures for functional limitation used in these surveys were developed for various purposes; therefore, there is no single unified approach to estimating the number of children with activity limitations. It is estimated that 2 percent of all disabled children are missed by household-based surveys like NHIS-D (Hogan, et al, 1997), which is much less than the adult disabled because so few children are institutionalized. The NHIS-D showed that 1.3 percent of children have a mobility impairment, 0.9 percent have a self-care impairment, 5.5 percent have a communication limitation and 10.6 percent are limited in their learning ability (Hogan, et al 1997).

While measuring functional limitations has advantages over the diagnosis-based approach, it still has limitations. Using this method by itself may miss children who are functioning well but still need ongoing services or care.

## Service-Based Approach

Many CSHCN have a need for specialized services or primary and preventive services at a level above and beyond the level usually needed by children. Estimates developed using this approach would be possible when programs have sufficient service billing information to identify CSHCN. This approach, however, excludes children with chronic conditions who use services in small quantities.

## CLASSIFICATION SYSTEMS FOR DISABILITY

How narrowly or broadly one defines the CSHCN population has an impact on estimating a target population. Researchers conducting studies on disability, often use classical frameworks to define the various domains of disability. This is required if a researcher intends to identify persons with different types of disabilities or examine the effect of interventions on the extent of disability. There are three major classification systems used for this purpose: the National Advisory Board on Medical Rehabilitation Research model, the International Classification of Impairments, Disabilities and Handicaps developed by the World Health Organization; and a model proposed by Saad Nagi, from the Institute of Medicine.

### The National Advisory Board on Medical Rehabilitation Research Model

The National Advisory Board on Medical Rehabilitation Research, of the National Center for Medical Rehabilitation Research (NCMRR), established within the National Institute for Child Health and Development, developed a disability model following the July 1990 adoption of the Americans with Disabilities Act. The NCMRR model (NIH 1993) presents five aspects of disability:

1. **Pathophysiology:** the interruption of or interference with normal physiological and developmental processes or structures.
2. **Impairment:** the loss or abnormality of cognitive, emotional, physiological, or anatomical structure or function, including all losses or abnormalities, not just those attributable to the initial pathophysiology.
3. **Functional Limitation:** the restriction or lack of ability to perform an action in the manner or with the range consistent with the purpose of an organ or organ system.
4. **Disability:** the inability or limitation in performing tasks, activities, and roles to levels expected in physical and social contexts.
5. **Societal Limitation:** the restriction, attributable to social policy or barriers (structural and attitudinal), which limits fulfillment of roles or denies access to services and opportunities that are associated with full participation in society.

## International Classification of Impairments, Disabilities, and Handicaps (ICIDH)

The ICIDH model presents four aspects of disability:

1. **Disease:** the presence of a diagnosed condition.
2. **Impairment:** any loss or abnormality of psychological, physiological, or anatomical structure or function.
3. **Disability:** a restriction in the ability to perform essential components of everyday living.
4. **Handicap:** a limitation on the fulfillment of a role that is normal for that individual.

According to ICIDH a "handicap" is a consequence of a "disability" and a "disability" is a consequence of an "impairment." However, impairments do not necessarily lead to disabilities, nor do disabilities necessarily lead to handicaps. Most importantly, this model suggests a detailed classification system that offers the potential for detailed needs assessment.

### Institute of Medicine/Saad Nagi Model

The NCMRR model builds heavily on the Nagi model. The Nagi model presents four aspects of disability:

1. **Pathology:** interruption or interference of normal bodily processes (at the cellular level).
2. **Impairment:** any loss or abnormality of psychological, physiological, or anatomical structure or function.
3. **Functional Limitation:** restriction or lack of ability to perform an action or activity in a manner considered normal that results from an impairment.
4. **Disability:** a restriction in the ability to perform essential components of everyday living.

## OTHER MODELS OR DEFINITIONS OF DISABILITY

### Framework Proposed by Ruth Stein, et al, for the QuiCCC

Ruth Stein, et al (1993) developed a questionnaire for identifying children with chronic conditions (QuiCCC) based on a conceptual framework also developed by her and her colleagues.

This framework defines ongoing health conditions as disorders that:

- I. Have a biologic, psychologic, or cognitive basis, and
- II. Have lasted or are virtually certain to last for at least 1 year, and
- III. Produce one or more of the following sequelae:
  - A. Limitation of function, activities, or social role in comparison with age peers in the general areas of physical, cognitive, emotional, and social growth and development.
  - B. Dependency on one of the following to compensate for or minimize limitation of function, activities, or social role:
    1. Medications
    2. Special diet
    3. Medical technology

4. Assistive device
  5. Personal assistance
- C. Need for medical care or related services, psychological services or educational services over and above the usual for the child's age, or for special ongoing treatments, interventions, or accommodations at home or in school.

## National Association of Children's Hospitals and Related Institutions (NACHRI) Classification System

The National Association of Children's Hospitals and Related Institutions (NACHRI) developed a classification system to identify individuals who have a congenital or chronic condition expected to last 12 months or longer (Muldoon, et al 1997). The system relies on the International Classification of Diseases, Ninth Edition, Clinical Modification (ICD-9-CM) codes that classify chronic disease by body system, condition category, severity level and disease progression. Acute conditions are not included in this system.

The following are key concepts of the NACHRI system:

**Chronic health condition:** defined as a physical, mental, emotional, behavioral or developmental disorder expected to last 12 months or longer or having sequelae that last 12 months or longer and requires treatment or monitoring. Approximately 4,000 of the 15,000 ICD-9-CM codes met these criteria.

**Severity level of diagnosis:** each diagnosis is given an initial severity level based on expected complexities and costliness of all health care services over a 12-month period.

**Severity level of person:** each person is assigned a severity level based on the severity level of the diagnosis, disease progression, interactive effects of multiple conditions, and supplemental status indicators.

**Disease progression:** each diagnosis is assigned to a disease progression type based on the expected course of the disease and treatment goal: cure/substantially improve, substantially improve/continuous treatment, status/improve function, progressive, supportive care, or mixed course.

**"At-risk" categories:** conditions that do not meet the criteria used for a chronic condition but usually require services of an amount and type greater than that for not chronically ill persons and place the individual at risk for a chronic condition.

The NACHRI approach is limited in that it relies on the accuracy of the ICD-9-CM codes and on the medical diagnosis. Its use involves the analysis of very large claims data sets, such as Medicaid and hospital claims data.

## Definition from the Federal Bureau of Maternal and Child Health

The federal Bureau of Maternal and Child Health (of the Health Resources and Services Administration (HRSA) in the Department of Health and Human Services (DHHS) which administers the Title V MCH Block Grant) defines children with special health care needs as:

*"...those children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally."*

The definition includes the following types of children: children with a diagnosis of a chronic illness, children who require services, and children at-risk. State Children with Special Health Care Needs programs (funded under Title V) have historically targeted cardiovascular, neurological and orthopedic

conditions such as congenital heart defects, cerebral palsy and spina bifida. These types of conditions have a relatively stable incidence and prevalence and are relatively rare and therefore can be estimated reliably. However, there are a group of conditions that are new and/or increasing or changing in prevalence and incidence. These conditions include psychiatric, emotional and learning disorders, chronic infectious diseases (e.g., AIDS, hepatitis, etc.) and asthma.

## Definition Using State Program Eligibility

The target population of CSHCN may be described using program *diagnostic eligibility*. This definition usually includes diagnostic, age and income criteria. Although this definition is limited to those eligible for a program, it can be useful to focus on a population that the program is in a position to address or a population that is "convenient" to measure. Program definitions that may be used include SSI, rehabilitation services and special education. It may also be helpful to compare the size of the population served by each program and how that population is geographically distributed within a state.

## Americans with Disabilities Act (ADA)

The Americans with Disabilities Act (ADA) defines an individual as having a disability if the individual meets one of the following criteria:

1. have a physical or mental impairment that limits one or more of the major life activities,
2. have a record of such impairment, or
3. be regarded as having such an impairment.

This definition is important in that many legal battles over access for the "disabled" will be fought based on it. Any person attempting to access any public service or structure, who requests assistance or reduction in physical barriers due to having a disability, will be judged according to this definition.

## The Physical-Mental Continuum

The Research Consortium on Chronic Illness in Childhood has identified a Physical-Mental continuum for describing a child with a chronic health condition. Each item on the continuum has a low and high end of a scale identified.

Duration	Brief----- Lengthy
Age of onset	Congenital----- Acquired
Limitation of age-appropriate activities	None----- Unable to conduct
Visibility	Not visible----- Highly visible
Expected survival	Usual longevity----- Immediate threat to life
Mobility	Not impaired----- Extremely impaired
Physiologic functioning	Not impaired----- Extremely impaired
Cognition	Normal----- Extremely impaired
Emotional/social	Normal----- Extremely impaired
Sensory functioning	Not impaired----- Extremely impaired
Communication	Not impaired----- Extremely impaired
Course	Stable----- Progressive
Uncertainty	Episodic----- Predictable

## THE ROLE OF SOCIODEMOGRAPHIC FACTORS IN ESTIMATING DISABILITY

Socioeconomic status is a fundamental correlate of disease because it affects access to important resources as well as affects whether an individual is exposed to harmful agents or hazards (Hogan, et al, 1997). The sociodemographic circumstances of a child's family circumstances are central to the understanding of disability, including identification, diagnosis, treatment and rehabilitation response (Newacheck 1992). Sociodemographic characteristics should always be examined when estimating children with disability. These characteristics include race and ethnicity, household structure (number of parents in household, other adults), education of guardians and family income (or presence of poverty).

## SOURCES OF DATA ON DISABILITY

### The Census Bureau

The Census Bureau (<http://www.census.gov>) collects a significant amount of information on disability status. The long form questionnaire on the 1990 Decennial census contained questions about disability, including questions about work disability, the ability to go outside the home alone, and the ability to take care of personal needs. This data set is the only one that can provide direct estimates of disability at sub-state geographic levels. Following the 1990 census, a Content Reinterview Survey was conducted which provided more specific information on limitations. Although the majority of the disability information is on the adult population, adult disability status can be used to establish need for and use of community resources. For example, if the unemployment status is higher for persons with disability in one community compared with another, it can be argued that increased resources should be applied to CSHCN in preparing them for transition to adulthood (e.g., job training, education, etc.).

The Census Bureau conducts three major surveys: the Decennial Census, Survey on Income and Program Participation, and the Current Population Survey (see *Module 7*).

#### The Survey on Income and Program Participation (SIPP)

The SIPP (<http://www.census.gov/hhes/sippdesc.html>) is a national household survey that began in 1984. An extensive and reasonably consistent set of questions relating to disability was asked in 1990, 1991, 1992 and 1993 SIPP. This survey is the preferred source among Census Bureau surveys for disability information. The disadvantage to using these data is the small sample size that restricts the use of the data below the regional level.

#### The Current Population Survey

The Current Population Survey (CPS) (<http://www.bls.census.gov/cps/cpsmain.htm>) is conducted monthly and the disability questions focus only on work. The CPS identifies persons who are out of the labor force because of a disability and, in each March survey since 1980, identifies persons who have health problems which "prevent them from working or limits the kind or amount of work they can do."

### The National Center for Health Statistics

The National Center for Health Statistics (NCHS) of the U.S. Department of Health and Human Services (DHHS) is the primary Federal source of data on the physical health of the U.S. population. The NCHS collects and publishes data on a variety of health topics.

## **The National Health Interview Survey**

The National Health Interview Survey (NHIS) (<http://www.cdc.gov/nchswww/index.htm>) is one of the major surveys of the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (<http://www.cdc.gov/>). Through NHIS, information concerning the health of the civilian noninstitutionalized population is collected through household interviews conducted throughout the United States. Each year, the survey consists of a basic set of questions on health, socioeconomic, and demographic items as well as one or more special questionnaires to obtain more detailed information on major current health issues. The NHIS has operated continuously since 1957, and its sample survey design has been reevaluated and modified following each of the last three decennial censuses of the U.S. population.

The core questionnaire includes the following types of basic health and demographic questions:

1. Demographic characteristics of household members, including age, sex, race, education, and family income.
2. Disability days, including restricted-activity and bed disability days, and work- and school-loss days occurring during the 2-week period prior to the week of interview, as well as days spent in bed during the last 12 months.
3. Physician visits occurring during the same 2-week period, the interval since the last physician visit, and the number of visits during the last 12 months.
4. Acute and chronic conditions responsible for these days and visits.
5. Long-term limitation of activity resulting from chronic disease or impairment and the chronic conditions associated with the disability.
6. Short-stay hospitalization data, including the number of hospital episodes during the past year and the number of days for each stay.

Interviews are conducted each week throughout the year in a probability sample of households. The interviewing is performed by a permanent staff of interviewers employed by the U.S. Bureau of the Census. Data collected over the period of a year form the basis for the development of annual estimates of the health characteristics of the population and for the analysis of trends in those characteristics.

All adult members of the household 17 years of age and older who are at home at the time of the interview are invited to participate and to respond for themselves. Information for children and for adults not at home during the interview is provided by a responsible adult (19 years of age and over) residing in the household. Between 65 and 70 percent of the adults 17 years of age and over are self-respondents. Generally, a random subsample of adult household members is selected to self-respond to additional questions on current health topics that vary from year to year. Depending on the household size and the nature and extent of health conditions of household members, the length of the interview ranges between 20 and 90 minutes.

The households selected for interview each week are a probability sample representative of the target population. Data are collected from approximately 49,000 households including about 132,000 persons in a calendar year. Participation is voluntary; confidentiality of responses is guaranteed. The annual response rate of NHIS is over 95 percent of the eligible households in the sample.

## **National Health Interview Survey Supplements Relevant to Children's Health**

NHIS 1990 Special Topics:

- Assistive Devices

NHIS 1991 Special Topics:

- Unintentional injuries

- Child health (includes childhood immunization; use of seat belts and safety seats; use of headgear and mouth guards during organized athletic activities; and, information on functional disabilities)
- Health promotion and disease prevention

NHIS 1992 Special Topics:

- Youth Risk Behavior Survey (youths 12-24)

NHIS 1993 Special Topics:

- Childhood immunizations (children <6 in each family with age-eligible children)
- Family resources (asked about all family members)

NHIS 1994 Special Topic:

- Survey on Disability (see below)

## **National Health Interview Survey on Disability**

### ***The National Disability Survey***

(<http://www.cdc.gov/nchswww/products/catalogs/subject/nhis/diswrit.htm>) is the first comprehensive survey of persons with disabilities, including children with disabilities. The survey was administered in two separate phases in 1994-95. Phase I included core NHIS items and a special set of items related to disability. This survey was intended to serve as a screen to identify persons with disabilities. Phase II was administered 6 to 9 months after Phase I to persons identified in Phase I as having a disability. The phase I survey was administered to 73,000 households with a total of 186,000 individuals.

Proposed data release dates are as follows:

Phase 1, 1994: July 1996

Phase 1, 1995: January 1998

Phase 2, 1994: February 1998

Phase 2, 1995: March 1998

## **Other Relevant Surveys Conducted by NCHS**

### ***National Hospital Discharge Survey (NHDS)***

The NHDS (<http://www.cdc.gov/nchswww/products/catalogs/subject/nhds/nhds.htm>) is a continuing nationwide sample survey that gathers information each year on patients (excluding newborn infants) discharged from a sample of non-Federal short-stay and specialty hospitals in the U.S. Unfortunately, because relatively few children are hospitalized each year and the NHDS does not oversample the child population, estimates are unreliable except for the most prevalent conditions.

### ***Longitudinal Follow-up to the National Maternal and Infant Health Survey (1991)***

This survey (<http://www.cdc.gov/nchswww/products/catalogs/subject/mihs/lfnmih.htm>) was conducted among mothers who were initially identified in the 1988 National Maternal and Infant Health Survey (NMIHS). Information contained on this survey may be linked to the birth outcomes identified in the NMIHS survey. Extensive information was obtained about the mother and child, making this survey one of the most important resources for health information on children ages 3 to 4 years of age.

## USING NATIONAL DATA TO DEVELOP SYNTHETIC ESTIMATES

National surveys are conducted using sampling methods that provide reliable and valid estimates for the United States as a whole and for very large subregions (e.g., West, South, etc.). Sample size and sampling design prevent the use of these data to provide direct estimates for smaller geographic areas. In order to make state and local estimates of measures from national surveys, synthetic estimates may be used. This involves applying summary proportions generated from the national data and applying them to state or local census data.

Synthetic estimation involves the use of values of a variable of interest from a geographic area and/or time period other than the geographic area and time period of the estimate being produced.

Before discussing synthetic estimation further, other considerations of using national survey data must be understood.

### National Survey Data Are Weighted

In a national sample survey, such as the National Health Interview Survey, each individual is assigned a weight based on a complex sampling design. Some groups are oversampled. When analyzing weighted data, analysis must account for each individual's weight. After weighting is accounted for, the final estimate represents the total number of individuals for the nation. For example, a sample of 16,000 persons may represent, in the analysis, 24 million persons. Information about how the data were weighted is usually available in the documentation which accompanies the file. In the NHIS data files each record includes a variable which accounts for that individual's total weight in the survey.

### Using Published Tables to Obtain Indirect Estimates

In lieu of using a data file to develop estimates, one can use published data tables. Advantages of using published tables are that the estimates are already weighted and that no data processing skills are required. The primary disadvantage to this method is that you must use the estimates and the stratification groups provided by the authors.

### Creating Estimates from a Data File Directly

Using the data file itself offers more flexibility to create a greater number of estimates for a variety of population groups. The majority of national survey data are now available in CD format and packaged with software to allow some manipulation of the data file.

## Creating a Synthetic Estimate

All of the national data-sets discussed above can be used to create synthetic estimates of the target population of CSHCN. The following example shows how a synthetic estimate can be calculated for the number of children ages 17 years and under with activity limitation in State X. The formula below shows the weighted percent of children with activity limitation to be 6.8 percent (taken from the 1994 NHIS Disability Supplement) using the data from the table on the next page.

$$\frac{4,743,842}{70,023,660} = 0.068$$

<b>Characteristic</b>	<b>All ages 17 years and under</b>
All children	70,023,660
Activity Status	
<i>Not limited</i>	65,279,818 (93.2%)
<i>Limited</i>	4,743,842 (6.8%)

If the number of children ages 0-17 in State X is 800,000 then the estimated number of children with activity limitation in State X is 53,600. This was obtained using the following formula:

$$\begin{aligned} \text{proportion of children with activity} &\times \text{the number of children} = \text{the estimate of the number} \\ \text{limitations in the national survey} &\text{ in State X} && \text{of children with activity} \\ & && \text{limitations in State X} \\ & && \text{or} \\ & && \text{using actual numbers:} \\ & && 0.0068 \times 800,000 = 54,400 \end{aligned}$$

In many cases these synthetic estimates are better than the direct estimate collected locally. This is because many local data collection efforts fail to have adequate sample size to generate stable estimates for many populations of interest.

## Potential Biases Associated with Creating Synthetic Estimates

Using data that have not been collected directly from the population of interest can introduce potential bias in the estimates that one should be aware of. Biases may differ depending on the application because the synthetic estimate will be a better representation of reality in some population domains than in others. To use national data to estimate target populations in ALL areas, the data must be stratified on population characteristics related to the indicator being estimated (e.g., age, sex, etc.).

## Test Yourself

### Developing a State Estimate for CSHCN

The first step in developing an estimate is to identify which characteristics of CSHCN you want to measure. Refer to the discussion on defining the population in Module 1 and refer to the section on synthetic estimates in Module 3 for more information on the method. Tables 1-8 may be found on pages 249-254.

Tables used in the exercises were produced using the *SETS* software that accompanies the CD-ROM version of the 1994 National Health Interview Survey on Disability (NHIS-DS). All estimates are based on weighted data. The state data table was created using data from the Census Bureau, also available on CD-ROM.

Table 3 includes age stratified estimates of children with activity limitation (taken from the NHIS-DS). Table 2 includes summary data by age and poverty status for State X.

### What is the expected number of children in State X ages 0-5 with activity limitation?

Table 3 shows the stratified estimate of children ages 0 to 5 with activity limitation to be 830,996 or 3.4% of children surveyed in the age group.

Table 2 shows the number of children ages 0 to 5 in State X to be 1,018,444.

The synthetic estimate of children ages 0 to 5 years with activity limitation can be computed as:

$$1,018,444 \times 0.034 = 34,627 \text{ children}$$

### What is the expected number of children in State X ages 0-11 with activity limitation?

Table 3 shows the stratified estimate of children with activity limitation from the national data-set:

ages 0 to 5	3.4%
ages 6 to 11	8.3%

Table 2 shows the following number of children in these age strata in State X:

ages 0 to 5	1,018,444
ages 6 to 11	1,211,253

The synthetic estimate of children ages 0 to 11 years with activity limitation can be computed as:

Age	National Estimate	State X Population	Synthetic Estimate
ages 0 to 5	3.4%	1,018,444	34,627
ages 6 to 11	8.3%	1,211,253	100,534
<b>Total</b>		2,229,697	135,161

$$135,161 / 2,229,697 = 0.061 \text{ or } 6.1\%$$



# Creating Target Population Estimates Using National Survey Data Exercises and Solutions

The data used in this exercise section are from the National Health Interview Survey on Disability, Phase 1, developed by the National Center for Health Statistics (NCHS). Tables 1, and 3 through 8 provide the data on some characteristics of the children with special health care needs (CSHCN). These tables were produced using the *SETS* software that accompanies the CD-ROM version of the 1994 National Health Interview Survey on Disability. Table 2 includes summary data by age and poverty status for State X. These type of data are also available on CD format from the Census Bureau on Summary Tape File 3.

## Exercise 1

### Estimating the number of children with a specified condition

Table 1 provides a sample of prevalence measures.  
Table 2 contains summary population data for State X.

Use information from Table 1 and Table 2 to answer the following questions:

- a. What is the expected number of children ages 0-5 in State X with a learning disability?
- b. What is the expected number of children ages 0-17 in State X with cerebral palsy?

## Exercise 2

### Estimating the number of children with diminished functional status

Table 3 provides a sample of proportions of children with functional limitations.  
Table 2 contains summary population data for State X.

Use information from Table 2 and Table 3 to answer the following questions:

- a. What is the expected number of children in State X ages 12-17 having difficulty with strenuous activity?

- b. What is the expected number of children in State X ages 0-17 with activity limitation?

### **Exercise 3**

#### **Estimating the number of children with a need for specialized services**

Table 4 provides a sample of summary data describing health service utilization among children.  
Table 2 contains summary population data for State X.

Use information from Table 2 and Table 4 to answer the following questions:

- a. What is the expected number of children in State X ages 12-17 who visit a doctor or specialist on a regular basis?
- b. What is the expected number of children in State X ages 0-17 who receive therapy in or out of the home?

### **Exercise 4**

#### **Estimating the number of children considered by others to have a disability**

Table 5 provides sample proportions of children considered by others to have a disability.  
Table 2 contains summary population data for State X.

Use information from Table 2 and Table 5 to answer the following questions:

- a. What is the expected number of children in State X ages 12-17 considered by others to have a disability?
- a. What is the expected number of children in State X ages 0-17 considered by others to have fair to poor health?

### **Exercise 5**

#### **Estimating various disability measures controlling for one other factor (poverty status)**

Table 6 provides a sample of measures from previous tables controlling for poverty.  
Table 2 contains summary population data for State X.

Use information from Table 2 and Table 6 to answer the following questions:

- a. What is the expected number of children in State X ages 0-17, adjusting for poverty status, with an activity limitation?
- b. What is the expected number of children in State X ages 0-17, adjusting for poverty status, considered by others to have fair or poor health?

## Exercise 6

### Developing a combined estimate for disability

Table 7 provides two tables generated directly from the *SETS* program of two mutually exclusive estimates of disability.

Table 8 provides a combined estimate using data from Table 7.

Table 2 contains summary population data for State X

Use information from Table 2 and Table 8 to answer the following questions:

- a. What is the expected number of children in State X ages 0-17 with activity limitation or fair or poor health?

#### Code book names used by NCHS for measures used in this module (1994 National Health Interview Survey on Disability, Phase 1)

Measure	Variable name
Learning disability	LEARNR
Mental retardation	RETARDR
Cerebral palsy	CERPALS
Muscular dystrophy	MUSCDYSR
Spina bifida	SPNBIFR
Cystic Fibrosis	CYSFIBR
Activity limitation	LATOTAL
Difficulty with strenuous activity	DIFSTACT
Goes to the doctor or specialist regularly	REGDR
Receives therapy in or out of the home	TXHOME12=yes or TXSCHOOL=yes
Respondent considers person to have a disability	RPPERDIS
Respondent considers this person to have fair or poor health	HEALTH = fair or poor

**Table 1**  
**Summary data describing the prevalence of specific conditions**  
**amongst children under age 18**

(1994 National Health Interview Survey on Disability, Phase 1)

Characteristic	All ages 17 years and under	0-5 years	6-11 years	12-17 years
All Children	70,023,660	24,507,881	23,196,284	22,319,495
Learning Disability	2,284,385 (3.3%)	148,401 (0.6%)	1,014,431 (4.4%)	1,121,553 (5%)
Mental Retardation	242,877 (0.3%)	44,356 (0.2%)	92,917 (0.4%)	105,604 (0.5%)
Cerebral Palsy	136,913 (0.2%)	42,972 (0.2%)	61,281 (0.3%)	32,660 (0.1%)
Muscular Dystrophy	21,518 (0.03%)	----	12,768 (0.06%)	8,750 (0.04%)
Spina Bifida	19,783 (0.03%)	----	13,140 (0.06%)	6,643 (0.03%)
Cystic Fibrosis	10,955 (0.02%)	4,950 (0.02%)	6,005 (0.03%)	---

-- no one identified in the group

Note: for conditions only the Yes and No responses applied to percents; "not ascertained or refused" were not included

**Table 2**  
**Census Data for State X on Selected Demographic Characteristics**

(1994 Census, Summary Tape File 3A.)

Characteristic	Number	Percent
<b>Total Population</b>		
Ages 0-17	2,946,365	----
Ages 0-5	1,018,444	34.6%
Ages 6-11	1,211,253	41.1%
Ages 12-17	716,668	24.3%
<b>Poverty Status</b>		
Ages 0-17 at or above poverty	2,450,860	83.2%
Ages 0-17 below poverty	495,505	16.8%
Ages 0-5 at or above poverty	254,785	25.0%

**Table 3**  
**Summary data describing functional limitations**  
**amongst children under age 18**

(1994 National Health Interview Survey on Disability, Phase 1.)

<b>Characteristic</b>	<b>All ages 17 ages and un- der</b>	<b>0-5 years</b>	<b>6-11 years</b>	<b>12-17 years</b>
<b>All Children</b>	70,023,660	24,507,881	23,196,284	22,319,495
<b>Activity Status</b>				
<i>Not Limited</i>	65,279,818 (93.2%)	23,676,885 (96.6%)	21,262,861 (91.7%)	20,340,072 (91.1%)
<i>Limited</i>	4,743,842 (6.7%)	830,996 (3.4%)	1,933,423 (8.3%)	1,979,423 (8.9%)
<b>Difficulty with Strenuous Activity</b>	1,756,150 (2.5%)	272,141 (1.1%)	638,148 (2.8%)	845,861 (3.8%)

**Table 4**  
**Summary data describing health service utilization**  
**amongst children under age 18**

(1994 National Health Interview Survey on Disability, Phase 1)

<b>Characteristics</b>	<b>All ages 17 years and under</b>	<b>0-5 years</b>	<b>6-11 years</b>	<b>12-17 years</b>
All Children	70,023,660	24,507,881	23,196,284	22,319,495
Goes to the doctor or specialist on a regular basis	44,018,816 (5.7%)	858,353 (4.2%)	1,459,995(6.3%)	1,524,401 (6.8%)
Receives therapy in or out of the home	475,129 (0.7%)	198,195 (0.8%)	179,680 (0.8%)	48,776 (0.3%)

**Table 5**  
**Summary data describing perception of disability**  
**amongst children under age 18**

(1994 National Health Interview Survey on Disability, Phase 1)

<b>Characteristics</b>	<b>All ages 17 years and under</b>	<b>0-5 years</b>	<b>6-11 years</b>	<b>12-17 years</b>
All Children	70,023,660	24,507,881	23,196,284	22,319,495
Respondent considers this person to have a disability	1,724,343 (2.5%)	236,801 (1.2%)	705,498 (3%)	708,573 (3.2%)
Respondent considers this person to have fair or poor health	2,013,723 (2.9%)	564,386 (2.8%)	682,617 (2.9%)	663,207 (3.0%)

**Table 6**  
**Summary data describing various measures for children under**  
**age 18**

(1994 National Health Interview Survey on Disability, Phase 1)

<b>Characteris- tics</b>	<b>All ages 17 years and under</b>	<b>At or above poverty</b>	<b>Below poverty</b>
All Children	70,023,660	52, 304,455 (74.7%)	13,062,688 (18.7%)
Learning Disability	2,284,385 (3.3%)	1,576,074 (3%)	545,828 (4.2%)
Has an activity limitation	4,743,842 (6.7%)	3,085,866 (5.8%)	1,284,540 (9.9%)
Goes to the doctor or specialist on a regular basis	44,018,816 (5.7%)	3,165,330 (6.1%)	636,664 (4.9%)
Respondent considers this person to have fair or poor health	2,013,723 (2.9%)	1,035,694 (2%)	750,174 (5.7%)

\* The poverty category 'unknown' is not shown in table, therefore the numbers in the last two columns do not total to the figures in column "All ages 17 years and under."

**Table 7**  
**Tables from the NHIS on Disability, Phase 1, Using SETS**

<b>LATOTAL/LABELS</b>	
File: PERSON.DAT	
Records: Age<18	
Weight: WTFA	
LATOTAL	70023660.00
Unable to perform major activity	505274.00
Limited in kind/amount major activity	2975491.00
Limited in other activities	1263077.00
Not limited (includes unknowns)	65279818.00

<b>HEALTH/LABELS</b>	
File: PERSON.DAT	
Records: Age<18 AND LATOTAL=4 (or not limited)	
Weight: WTFA	
<b>HEALTH</b>	65279818.00
Excellent	34724617.00
Very Good	17909337.00
Good	10672016.00
Fair	1044213.00
Poor	89065.00
Unknown	840570.00

**Table 8**  
**Estimates of children with activity limitations and**  
**fair or poor health combined**

Children with activity limitations:

= All children - not limited

= 70,023,660 - 65,279,818 = 4,743,842 (6.8%)

Children with fair or poor health:

= fair health + poor health

= 1,044,213 + 89,065 = 1,133,278

Children who are activity limited OR have fair or poor health:

= children activity limited + other children in fair or poor health

= 4,743,842 + 1,133,278 = 5,877,120 (8.4%)

## Solutions

### Exercise 1a

$$\begin{aligned} &0.006 \times 1,018,444 \\ &=6,110 \end{aligned}$$

### Exercise 2a

$$\begin{aligned} &0.038 \times 716,668 \\ &=27,233 \end{aligned}$$

### Exercise 3a

$$\begin{aligned} &0.068 \times 716,668 \\ &=48,733 \end{aligned}$$

### Exercise 4a

$$\begin{aligned} &0.032 \times 716,668 \\ &=22,933 \end{aligned}$$

### Exercise 5a

$$\begin{aligned} &\text{At or above poverty} =142,150 \\ &\text{Below poverty} =49,055 \\ &\text{Adjusted total} =191,205 \\ &\{\text{Crude total} =197,406\} \end{aligned}$$

### Exercise 6

$$\begin{aligned} &0.084 \times 2,946,365 \\ &=247,495 \end{aligned}$$

### Exercise 1b

$$\begin{aligned} &0.002 \times 2,946,365 \\ &=5,893 \end{aligned}$$

### Exercise 2b

$$\begin{aligned} &0.067 \times 2,946,365 \\ &=197,406 \end{aligned}$$

### Exercise 3b

$$\begin{aligned} &0.007 \times 2,946,365 \\ &=20,624 \end{aligned}$$

### Exercise 4b

$$\begin{aligned} &0.029 \times 2,946,365 \\ &=85,445 \end{aligned}$$

### Exercise 5b

$$\begin{aligned} &\text{At or above poverty} =49,017 \\ &\text{Below poverty} =28,244 \\ &\text{Adjusted total} =77,262 \\ &\{\text{Crude total} =85,445\} \end{aligned}$$

## References

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